DOCUMENT RESUME

ED 292 247 EC 202 029

AUTHOR	Turnbull, Ann; Shaffer, Harriet
TITLE	Family State-of-the-Art Conference: A Summary of Conference Proceedings (Alexandria, Virginia, February 27-28, 1986).
INSTITUTION	Georgetown Univ. Child Development Center, Washington, DC.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	86
NOTE	83p.; Prepared by the National Center for Networking Community Based Services.
AVAILABLE FROM	CASSP Technical Assistance Center, Georgetown University, Child Development Center, Georgetown University Hospital, 3800 Reservoir Rd., N.W., Washington, DC 20007 ($4.00).
PUB TYPE	Collected Works - Conference Proceedings (021) -- Reports - Descriptive (141) -- Viewpoints (120)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Advocacy; Case Studies; Daily Living Skills; Delivery Systems; Demonstration Programs; *Disabilities; Emotional Development; *Family Involvement; *Family Life; Financial Needs; Health Needs; Helping Relationship; Individual Needs; Legal Aid; Leisure Time; *Needs Assessment; *Program Improvement; Public Policy; Sexuality; Socialization; *Social Services; Special Education; Vocational Education

ABSTRACT

These summarized proceedings focus on the positive aspects of knowing, living with, and loving a child or an adult with a disability and ways in which service providers and policymakers could be more responsive to special family needs. An introductory chapter defines a family and family life and outlines seven premises that shape the specification of needs and strategies for enhancing family life. The report then addresses five areas of family life: daily living and health; educational and vocational development; financial, legal, and advocacy issues; socialization, leisure, and sexuality; and emotional development. Each section begins with a vignette written by a participant to illuminate family life with a disabled person. Each section then presents a list of needs, recommended strategies to respond to those needs, a brief description of a model program, a summary table with cross references between strategies and needs, and two case studies. Recommendations involve such issues as accepting families' and disabled persons' desires for placements in integrated settings, providing flexibility in guidelines for funding services, and allowing families to decide which services they actually want to use. (JDD)

Family State-of-the-Art Conference

ED292247

A Summary of Conference Proceedings

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Family State-of-the-Art Conference

A Summary of Conference Proceedings

Prepared by Ann Turnbull
and Harriet Shaffer

For
Georgetown University Child Development Center
National Center for Networking Community Based Services

Funded through an Interagency Agreement between the
National Institute on Disability and Rehabilitation Research, (Formerly NIHR),
U.S. Department of Education and the Division of Maternal and Child Health,
U.S. Department of Health and Human Services

1986

These proceedings are dedicated to
Carol Inman,
colleague, good friend, and advocate
for families with special needs.

American families have changed drastically from the traditional American families of twenty years ago. Today's families consist of more single parents and two-wage earners than did families of the 1960's. Added economic burdens, increased stress, lack of leisure time, and less contact with the extended family due to geographic mobility also contribute to current changes in American families.

Families whose members have disabilities are undergoing the same stresses and are facing the same types of changes that other families face. The major difference is that families with disabled members have the added stresses of requiring special services; making sure that those services are available in their communities; dealing with a variety of professionals on a regular basis; and making sure that their member with special needs has the transportation and service plans necessary for receiving the services. In addition, families with special needs must balance their lives and give attention and support to the needs of all the family members. It is not easy, but many families are succeeding.

In an effort to discern what families actually need to help them maintain a successful and quality family life, the National Institute on Disability and Rehabilitation Research, within the Office of Special Education and Rehabilitative Services, convened a group of individuals specifically concerned with special needs families. The group members had sons and daughters with special needs, had special needs themselves, or were professionals with deep commitments to families whose members have disabilities. The group discussed the challenges, problems, and feelings of satisfaction most common to special needs families.

The discussions focused on the positive aspects of knowing, living with, and loving a child or an adult with a disability. Contrary to what is often believed by many individuals, those persons with special needs are not always a burden to their families. As with non-disabled persons, individuals with disabilities represent a combination of strengths and limitations. This meeting was different from others that have dealt with "the family" because it highlighted the strengths of people with disabilities.

The participants set forth statements of what families with special needs want from the various service systems on which they depend, particularly the availability of more integrated educational, recreational, and vocational opportunities. The group made recommendations regarding ways in which service providers and policy makers could be more responsive to the goals, values, and desires of people with disabilities and their families. This responsiveness involves issues such as accepting families' and consumers' desires for placements in integrated settings, flexibility in guidelines for funding services, and allowing families to decide which services they actually want to use.

The results of the group's discussions are summarized in this monograph. It is now up to families and professionals to work together to ensure that as many of these recommendations as possible are carried out and become realities. This is not an easy task, but it is one that needs to begin immediately.

Madeleine Will
Assistant Secretary
Office of Special Education
and Rehabilitative Services

PARTICIPANT LIST
FAMILY STATE-OF-THE-ART MEETING
OLD TOWN HOLIDAY INN
ALEXANDRIA, VIRGINIA
FEBRUARY 27-28, 1986

Kathleen Kirk Bishop, M.S.W.
Social Work Program
Special Division of MCH
5600 Fishers Lane, Room 7A-23
Rockville, MD 20857

Camille Catlett
Administration on Developmental Disabilities
Department of Health and Human Services
336 E Humphrey Building
200 Independence Avenue, S.W.
Washington, DC 20201

Irving Dickman
94 Kenilworth
Cranford, NJ 07016

Rebecca Fewell, Ph.D.
Experimental Education Unit WS-10
Child Development and Mental
Retardation Center
University of Washington
Seattle, WA 98195

Patsy Fordyce
7 McKinley Circle
Little Rock, AR 72207

Joyce Frieden
504 W. Taylor Run Parkway
Alexandria, VA 22314

Barbara Friesen, Ph.D.
Research and Training Center
for Seriously Emotionally
Disturbed Children
Portland State University
P.O. Box 751
Portland, OR 97207

David Gray, Ph.D.
National Institute on Handicapped and Rehabilitation Research
330 C Street, SW
Switzer 3070
Washington, DC 20202-2305

Sharon Hostler, M.D.
Children's Rehabilitation Center
2270 Ivy Road
Charlottesville, VA 22901

Carol R. Inman
Office of Special Education and
Rehabilitative Services
U.S. Department of Education
400 Maryland Avenue, S.W.
Mail Stop 2304
Washington, DC 20202

Naomi Karp, M.Ed.
National Institute of Handicapped and Rehabilitation Research
330 C Street, S.W.
Switzer 3070
Washington, DC 20202-2305

Judith Katz-Leavy, M.Ed.
Community Service Systems Branch
Division of Education and Service Systems Liaison
National Institute of Mental Health
5600 Fishers Lane, Room 11-C-23
Rockville, MD 20857

Roxane Kaufmann
Network Project
Georgetown University Child Development Center
3800 Reservoir Road, N.W.
Washington, DC 20007

Harvey Liebergott, Ph.D.
Office of Special Education Programs
Department of Education
Switzer 3086
330 C Street, SW
Washington, DC 20202-2313

Phyllis R. Magrab, Ph.D.
Georgetown University Child Development Center
3800 Reservoir Road, NW
Washington, DC 20007

Thomas Merluzzi, Ph.D.
1210 Black Oak Drive
South Bend, IN 46617

Cory Moore
Montgomery County Association for
Retarded Citizens
1160 Nebel Street
Rockville, MD 20852

Patricia Morrissey
Rehabilitation Services Administration
Department of Education
Switzer 3028
330 C Street, SW
Washington, DC 20202-2312

Herbert Schneiderman, M.D.
College of Medicine
Department of Pediatrics
University Hospital
750 East Adams Street
Syracuse, NY 13210

Karen Shannon
Sick Kids Need Involved People (SKIP)
216 Newport Drive
Severna Park, MD 21145

Colleen Starkloff
Paraquad, Inc.
4475 Castleman
St. Louis, MO 63110

Ann Turnbull, Ed.D.
Bureau of Child Research
University of Kansas
Lawrence, KS 66045-2930

Maria Vandevier
P.O. Box 643
Seiad Valley, CA 96086

Lisbeth Vincent, Ph.D.
Room 310 University Club
432 North Murray Street
University of Wisconsin
Madison, WI 53706

Deborah Walker, Ed.D.
Harvard School of Public Health
677 Huntington Avenue
Boston, MA 02115

Martha Ziegler
Federation for Children with Special Needs
312 Stuart Street, Second Floor
Boston, MA 02116

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I. INTRODUCTION

We would like to introduce ourselves to you. Some of us have a member of our family who has a disability. One of us is the father of a son who is blind. Another is the mother of an adult-aged daughter who has a physical disability, a speech impairment, and mental retardation. Still another has a husband with a physical disability. Our contributions to the group were forged from the living laboratories of our home and family lives and from the valuable lessons we have learned from being part of the broad local, state, and national networks of families who share the experience of disability.

In addition to family members, some of us are professionals representing a range of service systems and disciplines -- educators, a pediatrician, a psychologist, social workers, human service administrators, and a journalist. Our professional expertise and knowledge of state-of-the-art practice is incorporated into the recommendations. From our diverse perspectives, we reached consensus on family needs and strategies for strengthening families.

OUR GOAL IN PREPARING THIS DOCUMENT IS TO ENHANCE FAMILY LIFE WHERE THERE IS A MEMBER WITH A DISABILITY.

What do we mean by family life?

First, what is a family? Families can be comprised of many people -- parents, sons, daughters, husbands, wives, grandparents, aunts, uncles, cousins, in-laws, and friends. If you ask ten people to "describe the members of their family", you are likely to hear 10 different interpretations. Also the same family can experience wide variations at different points of the life-cycle depending upon births, deaths, marriages, divorces, children moving out on their own, children returning to the family home, and the need of elderly parents for special care. Because of this significant variability, we use the term, family, to refer to the unit of people who are related by blood, marriage, or deliberate association and who share responsibilities for meeting individual or collective needs.

Given our definition of family, we now turn to defining family life. We just stated that families have responsibilities for meeting individual and collective needs. The areas of those needs are the areas of family life. We have categorized the areas of family life and examples of just some of the needs in each area as follows:

Daily Living and Health Needs -- food purchasing and preparation, home maintenance, and health care and maintenance.

Educational and Vocational Needs -- school work; development of work ethic, career preparation, continuing education.

Financial, Legal, and Advocacy Needs -- generating income, overseeing insurance programs, advocating for non-discriminatory participation in public programs, acting on legal rights and responsibilities.

Socialization, Leisure, and Sexuality Needs -- developing social skills, maintaining interpersonal relationships, engaging in recreational activities, fulfilling sexual needs.

Emotional Needs -- developing a sense of belonging, developing positive self-esteem, expressing emotions and values.

What disabilities do we address?

We define disability broadly to cover a wide range of conditions -- physical disabilities, visual impairments, hearing impairments, speech/language impairments, emotional disorders, chronic illnesses, mental retardation, and learning disabilities. Each type of disability has some unique characteristics that create specific needs for families; however, families with members having different kinds of disabilities usually find that many of their needs are similar. Throughout this document we address the needs of families in a generic rather than idiosyncratic manner.

What do we believe about family life where there is a member with a disability?

Seven premises shape the specification of needs and development of strategies for enhancing family life included in this document. It is important for you to understand these premises as a basis for understanding and acting on the needs and strategies. These premises include:

1. Disability creates special needs in all areas of family life. Families with a member having a disability typically have an increase in the frequency and intensity of needs in all five areas of family life. For example, they may be unable to accept a job change that would include a promotion because they would lose insurance coverage (economic); they may need assistance with homemaking responsibilities because of a member being confined to bed (domestic living); or they may need specialized vocational training to learn to compensate for a disability and thus be

prepared for competitive employment (education, vocational development). These needs extend beyond those facing families whose members do not have a disability. These needs impact every member of the family -- not just the individual with a disability, his/her parents, spouse, or children. Family support should assist families in identifying and prioritizing their needs for all areas of family life and for all family members. The goal is for family life with a member with a disability to be a positive experience.

2. Individuals with a disability make positive contributions to their families. Many persons erroneously believe that individuals with a disability are always a burden to their family; to the contrary, typically individuals with disabilities contribute in positive ways to the five areas of family life. They earn paychecks (economic); participate in household chores (domestic); and can serve as a catalyst for family members to continue their own education (education/vocational development). As with all persons, individuals with disabilities represent a combination of strengths and limitations. They can simultaneously create special needs related to some tasks of family life and contribute positively to others. Strategies for supporting families should enhance the dignity of individuals with disabilities by recognizing their positive contributions.

3. Families have individualized needs requiring individualized responses from a continuum of appropriate services. No two families are exactly alike. Families vary in size, age, cultural background, ethnicity, religion, socio-economic status, geographical location, health status, coping styles, and personal values. These differences truly make a difference in the families' specific needs and in alternatives they perceive to be acceptable in meeting their needs. For example, minority and immigrant families need culturally and language-appropriate educational materials, positive role models from the same cultural/ethnic background, bilingual and bicultural service providers, immigration counseling and assistance, and respect for their attitudes and values related to the impact of disability. To accommodate the wide range of variation that exists among families, we recommend strategies based on the value of preference satisfaction which holds that persons (in this case families) should have an array of alternatives from which to choose in satisfying their own preferences. Actualizing the value of preference satisfaction requires a continuum of services to be available for all family members across the entire family life-cycle including early childhood, school-age, adolescence, young adulthood, empty-nest years, and elderly years. Through the process of individualization, families should take the lead in identifying the services that are responsive to meeting their own needs.

4. Family needs should be met within integrated community services and environments. A fundamental premise within the field of disability is that individuals with disabilities and their families are entitled to services within the least restric-

tive environment through the least intrusive means. Thus, preference should be given to the development of family support services that are an integral part of generic community services. For example, mental health services should be encouraged to develop services for all families, including those who have members with a disability. Another aspect of community integration is for families to receive support and assistance from the informal community networks -- neighbors, friends, churches and synagogues, and community organizations. It is a mistake to formalize and professionalize all family support; informal support within the community is an essential option for accomplishing preference satisfaction.

5. Families should have access to information. Surprisingly, much of the available information concerning family support generated from federally funded research is disseminated to professionals but is inaccessible to families. Research often becomes an end in itself rather than a means of enhancing family life because results are not translated into relevant family implications and made available to families. Coordinated links are needed between research and families to insure that families have access to state-of-the-art information. Another valuable source of information for families is from other families who experience similar needs. Efforts are needed to strengthen the effective networking of families at local, state, and national levels. Increasing access to information can empower families to resolve many of their own needs related to the five areas of family life.

6. Families need to expect confidently that their member with a disability will have a positive future. The most frequently expressed worry of families with a member with a disability is "What does the future hold?" Families express grave concerns about the availability of community programs; the continuation of federal and state policy protecting the rights of persons with disabilities; and at the most fundamental and human level--what will happen when the family members prominent in the individual's life die? Families need support and assistance in constructively and confidently moving into each new stage of the family life-cycle; it is at life-cycle transitional periods that families typically experience the most intense stress.

7. Strategies for enhancing family life must be cost-effective. From both a fiscal and ethical perspective, it is essential that cost-effectiveness be used as an important criteria in designing and implementing family support strategies in both the public and private sectors. Currently, the following "Murphy's Law" in the field of disability has been noted: "If your handicapped child only needs 10 minutes of assistance, you can only receive 24 hours of care, usually out of the home"*.

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* Wieck, C. (1985). The development of family support programs. In J. J. Agnosta & V. J. Bradley (Eds.), Family care for persons with developmental disabilities: A growing commitment. Boston: Human Services Research Insitute.

Such a policy emphasis toward exorbitant institutional cost and away from more cost-efficient family support is a trend that requires immediate reversal. It is an established fact that family support is more cost-effective than institutional support. Policy is needed to move strongly ahead with family support and to investigate the relative cost-effectiveness of a range of family support options provided within integrated community environments.

How is this report organized?

The remaining five sections of this report address each of the five areas of family life: Daily living and health; educational and vocational development; financial, legal, and advocacy; socialization, leisure, and sexuality; and emotional development. Each of these sections is comprised of five parts. These parts include:

1. Each section begins with a vignette written by a family member from our group. This vignette provides a "window" into family life and illuminates needs from the perspectives of persons who experience them.

2. A list of needs is included that is based on the seven premises about family life as previously described.

3. Strategies are recommended to respond to the needs. These strategies are presented in five groups according to the persons who we recommend taking responsibility for implementation. These groups include:

    a. Family - This can include any family member -- parents, grandparents, husband, wife, children, aunts, uncles.

    b. Professional Service Delivery System - Different disabilities require the expertise of different professionals. Persons assuming responsibility to implement these suggestions could include educators, psychologists, physicians, nurses, social workers, rehabilitation counselors, allied health professionals, speech clinicians and an array of others.

    c. Informal Community Network - We use the term "informal" to refer to community citizens who are not professionally trained in disability. Particular recommendations in this sub-section could be implemented by newspaper editors, television and radio commentators, merchants, Chambers of Commerce, civic groups, religious groups, neighbors, and citizens-at-large.

d. Trainers - Trainers include persons with the responsibility of providing preservice and in-service education. Two particularly effective national networks for providing training to families are the Parent Training and Information Centers and Independent Living Centers. We believe the resources of these networks should be expanded to enable them to assume broader training responsibilities. Other essential training resources include universities, university affiliated facilities, community colleges, state and local governmental agencies, and consumer organizations.

e. Policy-makers - Policy recommendations are aimed at local, state, and federal policy-makers in executive, legislative, and judicial capacities.

4. A brief description of one model program in each area is provided to demonstrate that effective models exist for implementing the recommendations.

5. A summary table is included to provide a cross-referencing of strategies and needs. By comparing the seven premises previously described to these summary tables, the translation of premises into needs and needs into strategies is clearly apparent. Thus, one can approach the strategies with confidence that they have integrity with fundamental beliefs and values about family life.

6. Two case studies are included describing reactions to this report of family members in families with disabilities.

In conclusion, we would like to re-state our goal:

To enhance family life where there is a member with a disability.

We genuinely hope that this document is a means to that end.

II. DAILY LIVING AND HEALTH NEEDS OF FAMILY LIFE

Window into Family Life: Domestic Living and Health Needs

As a single parent of three girls (aged 11, 10, and 5) and as a professional actively involved in my field, many demands are made on me and my time. Meeting obligations at home and work can be stressful, and, at best, I can only hope to do what I can in both domains. Like most other single parents I must live with the compromises I have to make -- most times I cope with this successfully! However, unlike most single parents, I have a daughter with a mental disability who, because of the severity of her disability, is unable to function independently. Thus, while quality child care, in general, is sorely needed for single parents, it is even more difficult to find for children like my daughter. Also, an evening out or a weekend away presents an even more major obstacle. Child care and respite care would relieve the stress and concern and allow for more personal growth and managing professionally. It can also be an inexpensive way to support parents keeping their child with a disability in the home versus costly institutionalization.

Thomas Merluzzi, Father

Our son David has autism. He is severely retarded, and is limited in speech and in social interaction. Despite his disabilities, David went to a regular preschool and was in completely integrated school programs, from the age of six to thirteen. Now he goes to our neighborhood junior high school, where he is in a homeroom with non-handicapped children, and takes gym and shop with them.

Because he needs help in learning the skills of domestic daily living, his school program includes training in bed-making, table-setting, house-cleaning and cooking. This training takes place in a nearby home. The program involves training in real community settings, rather than simulated ones, and he and his class go swimming at the YMCA, go to the library, buy food at a supermarket, and go to restaurants. His classwork even includes work training in the graduate office of a local university.

If David had been born in an earlier time, he would have lived in an institution, or stayed at home with no services. Thanks to Public Law 94-142, and to creative, dedicated teachers, administrators and volunteers, he is learning things which will prepare him for adult living, work and recreation in our community. We live in a relatively good community for handicapped services. Life for us would be much more difficult elsewhere. But even here, there is much room for improvement, particularly as David reaches adulthood.

Herb and Hillery Schneiderman, Parents

Daily Living and Health Needs

FAMILIES NEED . . .

To identify and meet the daily living and health needs of all members.

To create opportunities for the individual with a disability to contribute to meeting the daily living and health needs of the family.

To identify and operationalize the strengths of all family members related to daily living and health needs.

To access daily living and health assistance, planning and advocacy services that enhance dignity for family members.

To access daily living and health services that are tailored to individual needs.

To access daily living and health services that are coordinated across all stages of the family life-cycle.

To access daily living and health services within integrated community programs and settings.

To access information on state-of-the art practices related to daily living and health services, and particularly to have continual updates on changes in public and private health benefit packages.

To access daily living and health services that help insure a positive future for the individual with a disability.

To network with other families to share information and to offer support and friendship to one another.

To realize the greatest dividend from daily living and health services by insuring maximum cost-effectiveness.

Recommended Strategies to Meet Daily Living and Health Needs

What can family members do to meet daily living and health needs of a member with a disability? Families can:

F1 Identify the priority daily living and health needs of all family members and develop options for responding to them.

F2 Provide information to professionals on the priority daily living and health needs of the family and preferred options for responding to them.

F3 Consider the option of teaching daily living skills (e.g., managing responsibility and sharing in household management) and health management to the individual with a disability within the home setting.

F4 Identify the daily living and health strengths of the individual with a disability and develop future goals and opportunities to capitalize upon these strengths.

F5 Determine preferences for the type and extent of involvement in daily living and health planning and develop skills necessary for preferred style of involvement.

F6 Insure that each daily living and health instructional program prepares participants for the expectations of the next life-cycle stage.

F7 Advocate for daily living and health training to be carried out in natural settings such as the home, community and job sites.

F8 Identify the respite care needs desired by the family and locate resources to obtain preferred respite services.

F9 Network with other families and professionals to expand home health care resources and financial incentives that favor home over institutional care.

F10 Develop expertise in increasing time efficiency of meeting daily living and health care responsibilities.

F11 Advocate for health care needs to be met in preventative as well as treatment mode.

F12 Encourage community professionals who provide health services to develop expertise in disability issues to increase their effectiveness in responding to the needs of families who have a member with a disability.

F13 Engage in systematic future planning to determine the preferences of the individual with a disability for adult life

style, especially in regard to options for meeting responsibilities of daily living and heatlh needs.

F14 Become informed about the relative public and private cost of different options for meeting the daily living and health needs of families and advocate for options that are cost-effective.

What can the professional service delivery system do to better serve families with a member with a disability in meeting daily living and health needs? The professional service delivery system can:

PS1 Identify procedures for assisting families to identify and prioritize daily living and health needs of all family members and to develop options for responding to them.

PS2 Assist families in carrying out daily living and health needs instruction in the home setting.

PS3 Identify and communicate the daily living and health strengths of the individual with a disability to the family.

PS4 Insure that educational and vocational programs teach daily living and health care skills that are consistent with family needs and that contribute to increasing the individual's positive contributions to the family.

PS5 Develop procedures for assisting families to identify their preferences for involvement in daily living and health skill training and involve families according to their preferences.

PS6 Provide opportunities for individuals with a disability and their families to interact with positive role models related to daily living and health goals.

PS7 Encourage effective networking of families for the purpose of sharing daily living and health information and providing support.

PS8 Provide state-of-the-art information to families on topics such as health services, respite care, attendant care, accessibility, time management, behavior management, and problem-solving.

PS9 Recognize the value and role of attendants as a means of achieving personal independence for individuals with disabilities.

PS10 Develop coordinated comprehensive health care programs which are accessible to all individuals with disabilities across all stages of the life-cycle.

PS11 Establish the cost-effectiveness of daily living and health programs; and use this information to increase cost effectiveness and to advocate for programs that are fiscally sound.

What can the informal community network do to meet the daily living and health needs of families with a member with a disability? The informal community network can:

I1 Highlight the daily living and health needs successes of individuals with disabilities through the media.

I2 Highlight the role of respite and attendant care services to individuals with disabilities through the media.

I3 Develop volunteer programs to provide daily living and health instruction and support to individuals related to areas of their needs and interests.

I4 Provide opportunities for daily living skills training to be provided in natural settings including homes, stores, clinics, and laundromats.

I5 Provide peer counseling opportunities for individuals with disabilities and their families related to daily living/ health needs.

I6 Provide access to public spaces (e.g., stores, health centers) for all persons with disabilities related to daily living and health needs.

I7 Encourage networking of families for the purpose of sharing information and providing support related to daily living and health needs.

I8 Determine the cost effectiveness of meeting daily living and health needs of individuals with disabilities and disseminate this information through the public media.

What can trainers do to meet the daily living and health needs of families with a member with a disability? The trainers can:

T1 Incorporate into preservice training programs of all professionals with responsibilities for working with families information to enable them to establish constructive and individualized family-professional partnerships responsive to daily living and health needs.

T2 Incorporate the independent living philosophy and strategies into preservice training programs of all professionals with responsibilities for working with individuals with disabilities related to daily living and health needs.

T3 Develop comprehensive and sequential inservice training programs for all professionals with responsibilities for working with families to enable them to establish constructive and individualized family-professional partnerships responsive to daily living and health needs across all stages of the family life-cycle.

T4 Provide inservice training in various cultural and ethnic identities and values related to daily living and health needs.

T5 Provide training opportunities for all interested families to enable them to meet the needs of all family members in the area of daily living and health.

T6 Provide training opportunities to all interested persons in the informal community network to prepare them to contribute effectively to the daily living and health needs of individuals with disabilities.

T7 Provide continuing education opportunities to all interested individuals with disabilities to enable them to meet their needs in the area of daily living and health.

T8 Provide training for in-home supportive service providers to meet daily living and health needs.

T9 Train health care professionals about the value and role of attendants as a viable means of independence for people with disabilities.

T10 Provide accessible and comprehensive clearinghouses of information that family members can access to gain information on topics related to daily living and health needs and advocacy for creating options to meet those needs.

T11 Determine the cost effectiveness of alternative models of training related to daily living and health needs and use this information to develop fiscally sound training options.

What can policymakers do to better meet the daily living and health needs of families with a member with a disability? Policymakers can:

P1 Strengthen and/or adhere to existing Section 504 regulations in order to ensure equal access to federally funded programs and services by individuals with disabilities related to daily living and health needs.

P2 Provide funding for homemaking services for individuals with disabilities.

P3 Provide funding for flexible attendant services and allow for family members who provide these services to be paid.

P4 Lobby for uniformity of state laws so that individuals with disabilities are not excluded in some health insurance policies as they now are.

P5 Mandate access to federally funded health care for all individuals with disabilities.

P6 Lobby for removal of pre-existing conditions clauses in insurance policies which serve to exclude individuals with severe disabilities from health coverage.

P7 Provide funding to allocate up to 20 days of respite care to families with a member with a disability on an annual basis.

P8 Provide funding to develop a comprehensive and coordinated clearinghouse of information that can be easily accessed by family members to provide daily living and health information pertinent to all stages of the family life-cycle.

P9 Implement, monitor, and evaluate interagency agreements to insure coordinated and comprehensive programming in meeting daily living and health needs.

P10 Provide 12-month education as an option for all students with disabilities who would evidence significant regression in daily living skills if the educational program is terminated over the summer months.

P11 Require the development of a transition plan from secondary education to adult services by the age of 14 which identifies daily living and health goals and the educational strategies which will be followed to accomplish the goals.

P12 Require federally-funded research projects related to the daily living and health needs of individuals with disabilities and their families to disseminate information to families.

P13 Implement, monitor, and evaluate interagency agreements to insure the provision of coordinated and comprehensive transportation to meet daily living and health needs.

P14 Require projects receiving federal funds for the purpose of providing daily living and health services to document cost-effectiveness and use data as a guide in making future decisions.

Model Program Description: Strategies to Respond to Daily Living and Health Needs

The Family Support and Resource Center is designed to help families care for their family members with developmental disabilities at home by providing them with a break from responsibility. It is the purpose of the Agency to provide a central source for Information, Service Referral and Coordination, Respite Care and Family Support Services to assist families and their children or adults with developmental disabilities. The Respite Care Program helps families locate and secure trained respite workers to provide care for their family member with disabilities. Care can be arranged for a few hours, several days or a week. The Program provides several options for families to choose from: in or out of home respite, exchanging care with other families and an emergency service. Respite care is partially reimbursed by the Program for 140 hours or 14 days per year. Families in need may qualify for full reimbursement. The Family Support Program helps families with children who are disabled from birth to 22 years of age learn about and use supportive services available to them in the community. Families along with Family Support staff identify problems and develop service plans that outline a strategy to meet the unique needs of each family. Flexible funding may be used to purchase goods and services that are presently not available to the family. Items that may be purchased include architectural modifications, child care, medical care, equipment, transportation and other expenses that are related to the care of children with disabilities.

For more information contact:

Family Support and Resource Center
521 North Sherman Avenue
Madison, WI 53704

Phone: (608) 246-0414

Cross-Referencing of Needs and Strategies: Daily Living and Health

FAMILIES NEED:	Strategies Which Can be Implemented by: Family	Profes-sionals	Informal	Trainers	Policy-Makers
To identify and meet the daily living and health needs of all members.	F1 F10 F11	PS1 PS2 PS5		T1 T7	P1 P5 P9 P10
To create opportunities for the individual with a disability to contribute to meeting the daily living and health needs of the family.		PS4			
To identify and operationalize the strengths of all family members related to daily living and health needs.	F4 F5 F10	PS3	I1		
To access daily living and health assistance, planning and advocacy services that enhance dignity for family members.	F8	PS6 PS9	I2 I4	T2 T8 T9	P2
To access daily living and health services that are tailored to individual needs.	F2 F3 F5 F7 F15	PS4	I5	T4 T5	P3 P6 P7
To access daily living and health services that are coordinated across all stages of the family life-cycle.	F6 F13	PS10		T3	P11
To access daily living and health services within integrated community programs and settings.	F12		I3 I6	T6	P4 P9 P12 P13
To access information on state-of-the art practices related to daily living and health services, and particularly to have continual updates on changes in public and private health benefit packages.		PS8		T10	P8 P12

To access daily living and health services that help insure a positive future for the individual with a disability.	F13	PS6		T2	P11
To network with other families to share information to offer support and friendship to one another.	F9	PS7	I7		
To realize the greatest dividend from daily living/ health services by insuring maximum cost-effectiveness.	F14	PS11	I8	T11	P14

III. EDUCATIONAL AND VOCATIONAL AREA OF FAMILY LIFE

Window into Family Life: Educational and Vocational Needs

My 21-year-old daughter, Leslie Ellen, has multiple handicaps: mental retardation, a physical disability that requires the use of a wheelchair for ambulation, a speech defect, and a significant health problem -- two hemiplegic migraine attacks in the past have resulted in one-sided paralysis and total aphasia which only cleared after months of intensive therapy. She lived at home with her dad and me, her older sister Laurie and younger brother Kenny for her first 19 years; for the past two, she has resided happily in a group home, ten miles and twelve minutes away from us. While her handicaps may define Leslie for those who don't know her, those who do recognize a young woman of considerable charm, humor, musical ability, an acute sense of the dramatic, and an open, positive interest in people (at least those people she likes!). Born before P.L. 94-142 opened schoolhouse doors, Leslie spent six of her first nine years in private "preschool" programs searched for, funded, and sometimes transported to, by her family. Later she was enrolled in segregated, categorical public school programs into which she was not always successfully shaped and molded. Because of the multiplicity of her handicaps, she had limited school opportunities for "real world" vocational experiences and has transitioned -- temporarily -- into a sheltered workshop. Two time-limited community placements have proved to some of us that with appropriate support Leslie can be successfully involved in an actual job in an integrated setting. With the impetus of P.L. 94-142 and the exciting federal transition initiative, new expectations and attitudes are developing. It is clear to me that with some creative thought, trained personnel, and a lifetime planning approach by parents, schools, and adult provider agencies, more doors can open for all our future Leslie Ellens. Integrated neighborhood schools will house students with any handicap, meaningful curricula will emphasize community-based living skills and lead to vocational placement when school entitlement ends, appropriate models by adult service providers will sponsor supported employment opportunities in the community. "Least restrictive environment" will truly mean access to a world we can all share to whatever degree possible.

Cory Moore, Mother

Educational and Vocational Needs

FAMILY NEEDS . . .

To identify and meet the educational and vocational needs of all members.

To identify and operationalize the strengths of all members related to educational needs.

To access educational and vocational services that enhance dignity for all family members.

To access educational and vocational services that are tailored to individual needs.

To access educational and vocational services that are coordinated across all stages of the family life-cycle.

To access educational and vocational services that help insure a positive future for the individual with a disability.

To access educational and vocational services that are integrated into regular schools, job sites, and community settings.

To access information on state-of-the-art practices related to educational and vocational services.

To network with other families to share information and to support one another.

To realize the greatest possible dividend from educational and vocational services by insuring maximum cost-effectiveness.

Recommended Strategies to Meet Educational and Vocational Needs

What can family members do to meet educational and vocational needs of family members with a disability? Families can:

F1 Identify the priority educational and vocational needs of all family members and develop options for responding to them.

F2 Provide information to educational and vocational professionals on the priority needs of the family and preferred options for responding to them.

F3 Consider the option of teaching skills to the individual with a disability within the home setting.

F4 Identify the educational and vocational strengths of the individual with a disability and develop future goals to capitalize upon these strengths.

F5 Consider career options for the individual with a disability that are characterized by dignity and opportunities for advancement.

F6 Determine preferences for the type and extent of involvement in educational and vocational planning and develop skills necessary for preferred style of involvement.

F7 Advocate for educational and vocational opportunities that are responsive to individual needs, preferences, and goals.

F8 Insure that all family members have continuing education options across the full family life-cycle.

F9 Insure that each educational or vocational program prepares participants for the expectations of the next stage (e.g., preschools preparing for kindergarten; high schools preparing for adult needs).

F10 Advocate for educational training to be carried out in natural settings such as the home, community, and job sites.

F11 Provide numerous opportunities for the individual with a disability through family activities to participate in a variety of community settings and environments.

F12 Network with other family members to gain information about options for responding to educational and vocational needs.

F13 Develop a clear understanding of professional and informal community support options related to educational and vocational needs as a basis for learning where and how to access information.

F14 Engage in systematic future planning to determine the preferences of the individual with a disability for adult life-style and to insure that the educational and vocational programs are systematically preparing the person for their preferred options.

F15 Develop thorough knowledge on future options for the individual with a disability by visiting community programs, reading information about programs, talking with other families who have had a member in the programs, and determining the satisfaction and success of the individuals who have been enrolled in the program.

F16 Become informed about the relative public and private cost of different options for meeting educational and vocational needs of families and advocate for programs that have been determined to be cost-effective.

What can professional service delivery systems do to better meet educational and vocational needs of families with a member with a disability? Professional delivery systems can:

PS1 Identify procedures for assisting families to identify and prioritize educational and vocational needs of all family members and to develop options for responding to them.

PS2 Assist families in carrying out instruction in the home setting.

PS3 Identify and communicate the educational and vocational strengths of the individual with the disability to the family.

PS4 Insure that educational and vocational programs teach skills that are consistent with family needs and that contribute to increasing the individual's positive contributions to the family.

PS5 Provide information to families on career options for the individual with a disability characterized by dignity and opportunities for advancement.

PS6 Develop procedures for assisting families to identify their preferences for involvement in educational and vocational decision-making and involve families according to their preferences.

PS7 Provide relevant continuing education opportunities that enable individuals to advance in their careers and expand their range of interests consistent with their needs and preferences.

PS8 Develop sequential and coordinated curricula within all phases of educational and vocational programs to ensure that the transition from one program to another is as successful as possible.

PS9 Provide opportunities for individuals with disabilities and their families to interact with positive role models related to educational and vocational goals.

PS10 Design and implement public awareness strategies to increase educational and vocational opportunities within integrated community settings for individuals with disabilities.

PS11 Encourage effective networking of families for the purposes of sharing information and providing support related to educational and vocational needs.

PS12 Provide readily available information to families on topics such as community services, vocational training programs, post-secondary training programs, and advocacy organizations.

PS13 Establish the cost-effectiveness of educational and vocational programs and use this information to increase cost-effectiveness and to advocate for programs that are fiscally sound.

What can informal community networks do to better meet the educational and vocational needs of families with a member with a disability? Informal community networks can:

I1 Highlight the educational and vocational needs and successes of individuals with disabilities through the media.

I2 Develop volunteer programs to provide instruction to individuals with disabilities related to areas of their needs and interests.

I3 Provide mentor programs for individuals with disabilities to assist them in developing relevant skills for careers that offer dignity and opportunities for advancement.

I4 Assume responsibility for expanding employment options to provide increased opportunities for individuals with disabilities.

I5 Provide opportunities for on-the-job training and continuing education of employees.

I6 Provide opportunities for educational and vocational instruction to be provided in natural settings.

I7 Promote the utilization of public spaces (e.g., school buildings and libraries) to meet educational and vocational needs.

I8 Promote the utilization of community programs (e.g., art centers, religious services) to meet educational and vocational needs.

I9 Encourage effective networking of families for the purposes of sharing information and providing support related to educational and vocational needs.

I10 Determine the cost-effectiveness of meeting the educational and vocational needs of individuals with disabilities within integrated community settings and disseminate this information through the public media.

What can trainers do to better meet the educational and vocational needs of families with a member with a disability? Trainers can:

T1 Incorporate into preservice training programs of all professionals with responsibilities for working with families information to enable them to establish constructive and individualized family-professional partnerships responsive to educational and vocational needs.

T2 Develop comprehensive and sequential inservice training programs for all professionals with responsibilities for working with families to enable them to establish constructive and individualized family-professional partnerships responsive to educational and vocational needs.

T3 Provide training in various cultural and ethnic identities and values related to educational and vocational needs.

T4 Provide training opportunities for all interested families to enable them to meet the educational and vocational needs of all family members across all stages of the family life-cycle.

T5 Provide training opportunities to all interested persons in the informal community network to prepare them to contribute effectively to the educational and vocational development of individuals with disabilities.

T6 Incorporate into the educational curriculum of all elementary and secondary school students information about the needs and strengths of persons with disabilities.

T7 Incorporate career education training at all levels of the curriculum for individuals with disabilities.

T8 Provide information to individuals with disabilities and their families on career options that are characterized by dignity and opportunities for advancement.

T9 Provide training opportunities for individuals with disabilities and their families to participate in decision-making related to educational and vocational planning.

T10 Provide relevant and ongoing continuing education opportunities that enable individuals to advance in their careers and expand their range of interests consistent with their preferences.

T11 Provide training to educators and vocational professionals on the full life-span needs of individuals with disabilities and their families and on the sequential development of curriculum to address these life-span needs.

T12 Provide accessible and comprehensive clearinghouses of information that family members can access to gain information on topics related to education and vocational development.

T13 Determine the cost-effectiveness of alternative models of educational and vocational training and use this information to develop fiscally sound training options.

What can policymakers do to better meet educational and vocational needs of families with members with a disability? Policymakers can:

P1 Provide free appropriate public education for all individuals with disabilities beginning at birth.

P2 Require that secondary students with disabilities participate in the conference to develop their individualized education program unless there is a compelling reason to the contrary.

P3 Implement, monitor, and evaluate interagency agreements to insure coordinated and comprehensive programming in meeting educational and vocational needs.

P4 Provide 12-month education as an option for all students with disabilities who would evidence significant regression if the educational program is terminated over the summer months.

P5 Require the development of a transition plan from secondary education to adult services by the age of 14 which identifies vocational, residential, and social/interpersonal goals and the educational strategies which will be followed to accomplish the goals.

P6 Insure that all educational facilities provide for the placement of students with disabilities in the least restrictive educational setting (e.g., daycare, preschool, community colleges, universities).

P7 Require that vocational training be conducted in community-based job settings.

P8 Identify and implement incentives for sheltered workshops to provide training, placement, and ongoing support for competitive employment.

P9 Remove disincentives to employment for individuals with disabilities and provide incentives to employment which provide recipients encouragement to work without the loss of benefits, inlcuding medical benefits.

P10 Provide tax incentives to industries who employ persons with disabilities.

P11 Increase funding of sections of the Rehabilitation Act of 1973 which address vocational areas such as training and basic grants to states.

P12 Require federally funded research projects related to the needs of individuals with disabilities and their families to incorporate a dissemination plan that insures information will be made available to all family members.

P13 Provide funding to develop a comprehensive and coordinated clearinghouse of information that can be easily accessed by family members to provide information on educational and vocational needs across all stages of the family life-cycle.

P14 Implement, monitor, and evaluate interagency agreements to insure the provision of coordinated and comprehensive transportation to meet educational/vocational needs.

P15 Require projects receiving federal funds for the purpose of providing educational and vocational planning/assistance, legal, and advocacy services to document cost-effectiveness and use data as a guide in future funding decisions.

Model Program Description: Strategies to Respond to Educational and Vocational Needs

The University of Maryland/Montgomery County Public Schools Demonstration Model to Develop Integrated School and Community Service Delivery System for Severely Handicapped Students is ending its three-year federal grant and as of September, 1986, will be totally incorporated into the Montgomery County (Maryland) Public Schools services. Its five components are integrated classes, community-based instruction, parent input, after-school carryover, and transition to work and group homes. Sixty students, aged from six to 21, are in ten age-appropriate, self-contained classes, integrated into nine regular elementary, middle and senior high schools. Interactions between the students and their peers without disabilities are promoted during lunch and recess times and in nonacademic classes. Special Friends Clubs and activities are planned. Instruction takes place in the community on a regular basis so that students can learn to use stores, restaurants, public transportation, and leisure facilities such as the bowling alley, swimming pool and library. Parents are actively involved in developing goals and objectives, filling out a parent inventory at the beginning of the school year with the participation of their child's teacher, and, with the Project's Parent Facilitator, meet regularly for discussion and sharing. Short-term assistance after school and on weekends helps interested families assist in promoting goals and objectives in home and neighborhood settings. Vocational instruction takes place in actual job sites, increasing in time as the student gets older. Domestic skills are taught in student homes and group homes rather than in simulated settings.

For more information contact:

Dr. Thomas J. O'Toole

Montgomery County Public Schools
Office of Special and Alternative Education
850 Hungerford Drive
Rockville, MD 20850

Phone: (301) 279-3135

Cross-Referencing of Needs and Strategies: Educational and Vocational

FAMILY NEEDS:	Strategies Which Can Be Implemented by: Families	Profes-sionals	Informal	Trainers	Policy-makers
To identify and meet the educational and vocational needs of all members.	F1 F2	PS1 PS6	I1	T1 T2	P1 P4 P6 P11
To identify and operationalize the strengths of all members related to educational needs.	F4	PS3 PS4		T6	
To access educational and vocational services that enhance dignity for all family members.	F5	PS9	I3 I4	T6 T9	P2 P9
To access educational and vocational services that are tailored to individual needs.	F3 F6 F7	PS2 PS7	I5	T3 T10	
To access educational and vocational services that are coordinated across all stages of the family life-cycle.	F8 F9 F15	PS8		T4 T11	P3
To access educational and vocational services that help insure a positive future for the individual with a disability.	F14	PS9	I3	T7	P5
To access educational and vocational services that are integrated into regular schools, job sites, and community settings.	F10 F11	PS10	I2 I6 I7 I8	T5	P7 P8
To access information on state-of-the-art practices related to educational and vocational services.	F13	PS5 PS12		T12	P12 P13
To network with other families to share information and to support one another.	F12	PS11	I9		

To realize the greatest possible dividend from educational and vocational services by insuring maximum cost-effectiveness.	F16	PS13	I10	T13	P10 P15

IV. FINANCIAL, LEGAL, AND ADVOCACY AREA OF FAMILY LIFE

Window into Family Life: Financial, Legal, and Advocacy Needs

Erin was born six and one-half years ago appearing to be a normal infant, but very quickly her medical status changed to severe respiratory failure. Erin was fortunate because she was born in an era of rapid medical advancement in hospital acute care intervention which allowed her to live; for Erin could not, and still today cannot, survive on her own. Her survival depends on joining together medical knowledge, the equipment, and services necessary to sustain Erin's life. Major problems developed when we realized that Erin could not be removed from her life support systems. Our problems were: Can a child who is dependent on this type of support ever go home? Who will and how can this child be managed long term? Where does responsibility really lie for these kids? What does the future hold legally and economically for us as a family?

Kids like Erin live in hospital intensive care units for years, sometimes for their entire lives, not only because of their families' fear of the complexity and sophistication of the assistance the child needs to stay alive, but also because of unwillingness of the medical system to think there can be any other option. Developing medical, social, and educational plans for home care was not easy, but it was accomplished because of a commitment from everyone involved in Erin's life. There was never a question for us as Erin's family that she did not belong at home. But going home for Erin meant adapting the environment to meet not only her medical needs but also her social, emotional, and cognitive needs, and promoting normalization as well as finding the funds to pay for home care. This carefully orchestrated move from hospital to home has proven to be cost effective because in-hospital costs averaged $300,000-$500,000 per year while in-home care cost $100,000-$250,000 annually. More importantly, home care allows for family completeness and gives us the chance to love and nurture Erin's developing life.

Once Erin came home, there was a new set of questions and obstacles. My overriding concern is how I can be the parent as well as the advocate, trouble shooter, and manager for Erin's needs as well as the needs of our entire family. In the beginning, very few, if any, programs actually met Erin's needs, even though they all claimed to, which brought a new set of challenges--that of obtaining quality care. When we did find the services to meet Erin's needs, we were always afraid that when tomorrow came, the services would be gone; or the resources to pay for the services would be denied. However, an echoing question continues to be asked--Where does the responsibility really lie for these kids? Insuring a life with dignity through standards of care so that the risk our kids are faced with is that of their own condition, not a risk of an unprepared environment, continues to be a dream. In the beginning, working towards tomorrow was never a dream for it seemed we would never get past

today. But soon we did start dreaming about tomorrow not knowing how to get there, but wanting to go. The question of school without an IEP seemed remote, but one day there we were in kindergarten with a willing teacher and an open-minded school district to teach Erin with Erin's personal team providing all her supports. This was our dreaming coming true, Erin going to school where her three brothers began their school years.

But what about tomorrow? High technology children demand more from our society in dollars and resources than ever thought possible--but what our society hasn't considered is that these children, as with all disabled, can give back one day much more than could ever be given them if they are only given the chance.

Karen Shannon, Mother

Financial Needs

FAMILY NEEDS . . .

To identify and meet the financial, legal, and advocacy needs of all members.

To create opportunities for the member with a disability to contribute to the economic assets of the family.

To identify and operationalize the advocacy strengths of family members.

To access financial assistance/planning services, legal, and advocacy services that enhance dignity for family members.

To access financial assistance/planning services, legal, and advocacy services that are tailored to individual needs.

To access financial assistance/planning services, legal, and advocacy services that are coordinated across all stages of the family life-cycle.

To protect the legal rights of individuals with disabilities across all stages of the life-cycle.

To access financial assistance/planning services, legal, and advocacy services within integrated community programs and settings.

To access financial support that enables families to provide care for the individual with a disability in the home as contrasted to hospitals and institutions.

To access information on state-of-the-art practices related to financial assistance/planning services, legal, and advocacy services, and particularly to have continual updates on changes in public and private financial benefit packages.

To access services related to financial assistance/planning needs, and legal, and advocacy needs that help insure a positive future for the individual with a disability.

To realize the greatest dividend from financial assistance/planning services, legal, and advocacy services by insuring maximum cost-effectiveness.

Recommended Strategies to Meet Financial, Legal, and Advocacy Needs

What can family members do to better meet the financial, legal and advocacy needs of their member with a disability. Family members can:

F1 Identify the priority financial, legal, and advocacy needs of all family members and develop options for responding to them.

F2 Obtain financial planning information related to access to government benefits, insurance options, tax credits, estate planning, and the development of wills and trusts that is responsive to the individual needs of families across all stages of the life cycle.

F3 Obtain financial assistance of a non-stigmatizing nature to meet needs in all areas of family life based on eligibility criteria that consider income, number of dependents, and excess cost related to disability.

F4 Obtain advocacy services to insure the protection of legal rights for all family members.

F5 Become knowledgeable on guardianship laws and insure that the individual with a disability is provided with an educational program to expand decision-making capacity to the greatest extent possible as a means of avoiding adjudication of incompetence and the appointment of a guardian upon the age of majority.

F6 Identify the future economic potential and present economic contributions of the individual with a disability and develop a plan to accentuate strengths.

F7 Identify the advocacy strengths of the individual with a disability and provide support and encouragement to increase advocacy effectiveness across the life-cycle.

F8 Advocate with insurance companies and medicaid programs for financial assistance that respects the right of the individual with a disability to receive services in the home as contrasted to a hospital or institution.

F9 Encourage community professionals who provide financial planning, legal, and advocacy services (e.g., trust officers, financial planners, insurance adjusters, lawyers) to develop expertise in disability issues to increase their effectiveness in responding to the needs of families who have a member with a disability.

F10 Contribute to the development of a statewide and community-based clearinghouse of information to guide families and professionals in learning where and how to access financial

assistance/planning, legal, and advocacy services.

F11 Become informed about the relative public and private cost of different options for meeting the financial, legal, and advocacy needs of families and advocate for options that are cost-effective.

What can the professional service delivery system do to better meet the financial, legal and advocacy needs of the family member with a disability? The professional service delivery system can:

PS1 Develop and implement procedures for assisting families to identify and prioritize financial assistance/planning, legal, and advocacy needs of all family members and to develop options for responding to them.

PS2 Provide individualized financial planning information related to access to government benefits, insurance options, tax credits, estate planning, and the development of wills and trusts that is responsive to the needs of families across all stages of the life cycle.

PS3 Insure that families needing financial assistance have access to necessary resources to insure that basic family needs are met at all life-cycle stages.

PS4 Insure that families have access to legal services to insure the full protection of rights at all life-cycle stages.

PS5 Develop and teach educational curricula that prepare individuals with a disability to make positive financial contributions to their families.

PS6 Develop and teach educational curricula that prepare individuals with a disability to be successful self-advocates.

PS7 Develop and teach educational curricula to enable individuals with a disability to expand their decision-making capacity to the greatest extent possible as a means of avoiding adjudication of incompetence and the appointment of a guardian upon the age of majority.

PS8 Develop procedures for assisting families to identify their preferences for the type and extent of their involvement in advocacy and support families to be involved according to their preferences.

PS9 Develop ethical standards to guide the protection of legal rights of individuals with disabilities and assume responsibility for implementing the standards.

PS10 Encourage the development of competence related to pertinent disability issues by lawyers, trust officers, financial planners, and insurance adjusters to enable families to obtain assistance and services from "mainstreamed" service providers.

PS11 Provide state-of-the-art information to families on emerging models related to financial assistance/planning, legal, and advocacy services that are responsive to individual needs.

PS12 Develop strategies to update families as frequently as needed on changes in public and private financial benefits.

PS13 Establish the cost-effectiveness of financial assistance/planning, legal, and advocacy programs and use this information to increase cost-effectiveness and to advocate for programs that are fiscally sound.

What can informal community networks do to better meet the financial, legal and advocacy needs of the family member with a disability? The informal community networks can:

I1 Develop and implement citizen advocacy programs to enhance rights and opportunities for individuals with a disability and other family members.

I2 Identify families needing financial assistance and develop individualized options for responding that respect the dignity of the family.

I3 Highlight the advocacy needs and successes of individuals with a disability through the media.

I4 Assume responsibility for insuring non-discrimination for individuals with a disability in all community programs.

I5 Determine the cost-effectiveness of family and community support for individuals with a disability and disseminate this information through the media.

What can trainers do to better meet the financial, legal and advoacy needs of the family member with a disability? The trainers can:

T1 Incorporate into law school curricula coursework related to disability law and advocacy.

T2 Develop comprehensive and sequential inservice training programs for all professionals with responsibilities for providing legal and advocacy services to insure that they are knowledgeable about issues pertinent to disability.

T3 Incorporate into business school curricula coursework related to the economics of disability and financial planning related to issues of disability.

T4 Develop comprehensive and sequential inservice training programs for professionals with responsibilities for providing financial assistance and planning services to insure that they are knowledgable about issues pertinent to disability.

T5 Provide inservice training in various cultural and ethnic identities and values related to financial, legal, and advocacy needs.

T6 Provide training opportunities for all interested families to enable them to engage in systematic and comprehensive financial planning.

T7 Provide training opportunities for all interested families on their legal rights and strategies for effective advocacy to insure their rights.

T8 Provide accessible and comprehensive clearinghouses of information that family members can access to gain information on topics related to financial assistance/planning, legal rights, and advocacy.

T9 Determine the cost effectiveness of alternative models of training related to financial assistance/planning, legal rights, and advocacy and use this information to develop fiscally sound training options.

What can policymakers do to better meet the financial, legal and advocacy needs of the family member with a disability? The policymakers can:

P1 Enact federal legislation to shift major funding streams away from residential institutions and to community and family support programs.

P2 Replicate successful family support programs in every state to provide financial subsidies to enable families to meet the needs of their member with a disability in the home and community setting.

P3 Eliminate all policy incentives that favor out-of-home care and provide policy incentives that support families to remain intact (e.g., payment of families as health care providers, tax credits).

P4 Expand resources to Protection and Advocacy Agencies to insure that all families have access to legal and other advocacy services.

P5 Develop policy to provide for reimbursement of attorneys' fees for families who prevail in disputes.

P6 Monitor and enforce the implementation of the Rehabilitation Act.

P7 Support augmented funding of the Rehabilitation Act and retention of the rights and provisions contained therein.

P8 Enforce the Baby Doe provisions of the Child Abuse Act and Section 504 related to the denial of medical treatment to infants with disabilties.

P9 Increase levels of funding for psycho-social prevention of disabilities including support and training of teenage mothers, accident prevention, expansion of child abuse and neglect programs, and education in the effects of substance abuse.

P10 Increase levels of funding for bio-medical prevention of disabilities including immunization programs, prenatal care, nutrition, environmental hazards screening, and genetic counseling.

P11 Protect the current and prospective Social Security benefit levels and eligibility for persons with disabilities under the Social Security Act.

P12 Strengthen and implement fully the home and community-based waivers of the Medicaid program.

P13 Provide a non-age restricted personal tax exemption for any family with a member with a disability.

P14 Expand adoption programs of children with disabilities through specialized financial support.

P15 Expand services for populations who are underserved including minority and immigrant families, elderly persons, individuals with disabilities in the criminal justice system, and parents with disabilities.

P16 Promote legislation to end discrimination based upon disability for persons seeking to immigrate to the United States.

P17 Establish model state statutes for limited guardianship and encourage state implementation.

P18 Fund research to assess the cost-effectiveness of family versus institutional support.

P19 Fund research to establish baseline data on the economics of disability and procedures to use to establish the excess

cost of disability to individual families.

P20 Require federally-funded research projects related to financial planning/assistance, legal, and advocacy needs of individuals with disabilities and their families to disseminate information to families.

P21 Establish criteria for determining eligibility of families for financial assistance based on a combination of factors including income, number of dependents, and the excess cost related to the disability.

P22 Expand funding to develop a comprehensive and coordinated clearinghouse of information that can be easily accessed by family members to provide financial planning/assistance, legal, and advocacy information pertinent to all stages of the family life-cycle.

P23 Implement, monitor, and evaluate interagency agreements to insure the provision of coordinated and comprehensive transportation to meet financial planning/assistance, legal, and advocacy needs.

P24 Require projects receiving federal funds for the purpose of providing financial planning/assistance, legal, and advocacy services to document cost-effectiveness and use data as a guide in future funding decisions.

Model Program Description: Strategies to Respond to Financial Planning and Legal Needs

At the University of Kansas, the Department of Special Education and Bureau of Child Research have a joint project that assists families to plan for the future of their children with developmental disabilities and, indeed, for the future of the entire family. A major concern of families -- "What will happen to my child with a disability after I die?" -- raises financial, legal, and ethical issues of future planning. Professor H. R. Turnbull, a lawyer, has prepared materials that show families how to use private (family) assets as additional resources, over and above the federal social security benefits (Social Security Disability Income and Supplementary Security Income) and medical benefits (Medicaid and Medicare). His materials also deal with legal issues of competency and guardianship, the admission of the person to community and institutional residential options, and the restriction of the person's vulnerability to and responsibility for family-related activities (sterilization, abortion, termination of parental rights). In addition, his materials address not just what the law allows, but the ethical issues of how a family balances the interests of one of its members against the interest of all of its members. He has developed a trainer-of-trainers workshop model to disseminate these materials to families and professionals.

For more information contact:

H. R. Turnbull, III

Department of Special Education
340 Haworth Hall
University of Kansas
Lawrence, KS 66045

Phone: (913) 864-4954

Cross-Referencing of Needs and Strategies: Financial, Legal, and Advocacy

FAMILIES NEED:	Strategies Which Can Be Implemented By: Families	Profes-sionals	Informal	Trainers	Policy-makers
To identify and meet the financial, legal, and advocacy needs of all members.	F1	PS1 PS3	I1	T1 T2 T3 T4	P2 P21
To create opportunities for the member with a disability to contribute to the economic assets of the family.	F6	PS5			P11 P13 P14
To identify and operationalize the advocacy strengths of family members.	F7	PS6 PS8	I3	T7	
To access financial assistance/planning services, legal, and advocacy services that enhance dignity for family members.	F3 F4		I2	T6	
To access financial assistance/planning services, legal, and advocacy services that are tailored to individual needs.	F4			T5	P4 P12
To access financial assistance/planning services, legal, and advocacy services that are coordinated across all stages of the family life-cycle.	F2	PS2 PS4			P9 P10 P15
To protect the legal rights of individuals with disabilities across all stages of the life-cycle.	F5	PS9		T7	P6 P7 P8 P16 P17

To access financial assistance/planning services, legal, and advocacy services within integrated community programs and settings.	F9	PS10	I4		P23
To access financial support that enables families to provide care for the individual with a disability in the home as contrasted to hospitals and institutions.	F8				P1 P3 P18
To access information on state-of-the-art practices related to financial assistance/ planning services, legal, and advocacy services, and particularly to have continual updates on changes in public and private financial benefit packages.	F2 F10	PS11 PS12		T8	P20 P22
To access services related to financial assistance/planning needs, legal, and advocacy needs that help insure a positive future for the individual with a disability.	F5	PS7			P5
To realize the greatest dividend from financial assistance/planning services, legal, and advocacy services by insuring maximum cost-effectiveness.	F11	PS13	I5	T9	P19 P24

V. SOCIALIZATION, LEISURE, SEXUALITY AREA OF FAMILY LIFE

Window into Family Life: Socialization, Leisure, and Sexuality Needs

For parents of children with disabilities, one of the most difficult things very often is "letting go" or letting the "child" grow up. The youngster sees it only as being with peers and like peers; if the parent sees only the risks, she/he can become part of the problem.

A heart-in-mouth incident with our son Ken comes to mind. He was born legally blind and learning disabled, but we resolved to teach him whatever our first two children had learned. That included bike-riding -- which was fine so long as he was willing to restrict it to an athletic field and the quiet streets in our development. But then came the morning he announced he was going to ride to school "with the other kids." And he did, as two quaking parents watched him, waving but proud, terrorized by every motorist hurrying to work on that main artery. He made it, and kept on making it: he was now a little less "different."

Later, in his twenties, he made his decision to move out of our home--a milestone decision with which we concurred heartily. He began calling boarding houses and SROs in our area, and one day announced proudly that he'd found a vacancy he could handle on his SSI budget and was moving in--sight unseen--that weekend. We were dismayed by the neighborhood, so much so that we decided I'd better stay with the car--in broad daylight--while my wife went across the street with Ken. She was out faster than she'd gone in--it would have been great Hollywood comedy: "Let's go!" Later on when I saw the lobby, it was clear why. Most of the people had just been discharged from state institutions, were getting no community help, and were--looked--totally lost.

But Ken insisted. He simply refused to see what we saw. We went home without him, sticking to our principles--but shaking. We were right to worry, of course; during the next few years he was mugged three times, once badly enough to require stitches; all his valuables were stolen (we'd warned him); he had to move four times, and each new "home" seemed worse than the last.

But he never asked to move back in with us. Along the way he picked up a certain amount of "street smarts," and he survived. And he's now sharing an apartment with another young man, he's learned to shop some, and cook some, and budget some, and live on his own. Just as his friends do.

Irving Dickman, Father

Socialization, Leisure, and Sexuality Needs

FAMILIES NEED:

To identify and meet the socialization, leisure, and sexuality needs of all members.

To create opportunities for the member with a disability to contribute to the socialization and leisure time assets of the family.

To identify and operationalize the socialization strengths of family members.

To access services related to socialization, leisure, and sexuality needs that are tailored to individual needs.

To access socialization, leisure, and sexuality services that are coordinated across all stages of the family life-cycle.

To access socialization, leisure, and sexuality services within integrated community programs and settings.

To access information on state-of-the-art practices related to socialization, leisure, and sexuality training.

To access services related to socialization, leisure, and sexuality needs that help insure a positive future for the individual with a disability.

To network with other families to share information, and to offer support and friendship to one another.

To realize the greatest dividend from socialization, leisure, and sexuality services by insuring maximum cost-effectiveness.

Recommended Strategies to Meet Socialization, Leisure, and Sexuality Needs

What can family members do to better meet the socialization, leisure and sexuality needs of a family member with a disability? Family members can:

F1 Identify the priority socialization, leisure, and sexuality needs of all family members and develop options for responding to them.

F2 Display love and affection towards the individual with a disability as with any family member.

F3 Support the individual with a disability in developing friendships as the basis for meeting socialization, leisure, and sexuality needs.

F4 Insure that all family members have opportunities for leisure and a break from responsibilities.

F5 Recognize the sexuality needs of the individual with a disability and support the individual in creating options for expression.

F6 Provide information to professionals on the priority needs of the family and preferred options for responding to them.

F7 Identify the socialization, leisure, and sexuality strengths of the individual with a disability and develop future goals to capitalize upon these strengths.

F8 Determine preferences for the type and extent of involvement in socialization, leisure, and sexuality planning and develop skills necessary for preferred style of involvement.

F9 Advocate for socialization, leisure, and sexuality opportunities that are responsive to the individual's needs, preferences, goals.

F10 Network with other family members to gain information about options for responding to socialization,leisure, and sexuality needs.

F11 Develop a clear understanding of professional and informal community support options as a basis for learning where and how to access information.

F12 Engage in systematic future planning to determine the preferences of the individual with a disability for adult life style, especially in regard to personal relationships, marriage, and parenthood.

F13 Support the individual with a disability in making contraception choices based on individual needs and preferences.

F14 Participate in programs with an emphasis on recreation and establishing friendships among families.

F15 Advocate for socialization and leisure training to be carried out in natural settings such as the home, community, and job sites.

F16 Provide numerous opportunities for the individual with a disability, through family activities, to participate in a variety of community settings and environments.

F17 Become informed about the relative public and private cost of different service options related to socialization, leisure, and sexuality needs and advocate for programs that have been determined to be cost-effective.

What can professional service delivery systems do to better meet the socialization, leisure, and sexuality needs of a family member with a disability? Professional service delivery systems can:

PS1 Identify procedures for assisting families to identify and prioritize socialization, leisure, and sexuality values and needs of all family members and to develop individualized options for responding to them.

PS2 Identify and communicate the socialization, leisure, and sexuality strengths of the individual with the disability to the family.

PS3 Insure that educational programs teach socialization, leisure, and sexuality skills that are consistent with family needs and values and that contribute to increasing the individual's positive contributions to the family.

PS4 Develop procedures for assisting families to identify their preferences for the type and extent of involvement in socialization, leisure, and sexuality planning and involve families according to their preferences.

PS5 Provide relevant continuing education opportunities that enable individuals to be aware of socialization, leisure, and sexuality needs of the family member with a disability across all stages of the family life-cycle.

PS6 Develop sequential and coordinated curricula within all phases of socialization, leisure, and sexuality programs to insure that the transition from one program to another is as successful as possible.

PS7 Design and implement public awareness strategies to increase socialization and leisure activities within integrated community settings for individuals with disabilities.

PS8 Encourage effective networking of families for the purposes of sharing information and providing support related to socialization, leisure, and sexuality needs.

PS9 Provide readily available information to families on topics such as developing friendship skills, developing social skills, making available leisure activities, making decisions about contraception and preparing for parenthood.

PS10 Provide role models for families of adults with a disability who have developed creative and satisfactory options for responding to socialization, leisure, and sexuality needs.

PS11 Establish the cost-effectiveness of socialization, leisure, and sexuality programs and use this information to increase cost-effectiveness and to advocate for programs that are fiscally sound.

What can the informal community network do to better meet the socialization, leisure, and sexuality needs of a family members with a disability? The informal community network can:

I1 Highlight the socialization and leisure needs and successes of individuals with disabilities through the media.

I2 Develop volunteer programs to provide instruction to individuals with disabilities related to socialization, leisure, and sexuality needs and interests.

I3 Provide mentor programs for individuals with disabilities to assist them in developing friendships and social skills.

I4 Promote the utilization of public spaces (e.g., parks, recreational centers) to meet socialization, leisure, and sexuality needs.

I5 Promote the utilization of community programs (e.g., art centers, religious services, Planned Parenthood) to meet socialization, leisure, and sexuality needs.

I6 Encourage effective networking of families for purposes of sharing information and providing support related to socialization, leisure, and sexuality needs.

I7 Determine the cost-effectiveness of meeting the socialization, leisure, and sexuality needs of individuals with disabilities within integrated community settings and disseminate this information through the public media.

What can trainers to do better meet the socialization, leisure, and sexuality needs of a family member with a disability? Trainers can:

T1 Incorporate into preservice training programs of all professionals with responsibilities for working with families information to enable them to establish constructive and individualized family-professional partnerships responsive to socialization, leisure, and sexuality needs.

T2 Provide inservice training to educators in socialization, leisure, and sexuality needs of persons with disabilities.

T3 Develop comprehensive and sequential inservice training programs for all professionals with responsibilities for working with families to enable them to establish constructive and individualized family-professional partnerships responsive to socialization, leisure, and sexuality needs across all areas of family life.

T4 Provide training in various cultural and ethnic identities and values related to socialization, leisure, and sexuality needs.

T5 Provide training opportunities for all interested families to enable them to meet the socialization, leisure, and sexuality needs of all family members across all areas of family life.

T6 Provide training opportunities to all interested persons in the informal community network to prepare them to contribute effectively to the socialization, leisure, and sexual development of families.

T7 Incorporate into the educational curriculum of all elementary and secondary school students information about the socialization needs and strengths of persons with disabilities.

T8 Incorporate socialization, leisure, and sexuality training at all levels of the curriculum for individuals with disabilities.

T9 Provide training opportunities for individuals with disabilities to learn to make decisions and express choices related to socialization, leisure, and sexuality needs.

T10 Provide accessible and comprehensive clearinghouses of information where family members can gain access to information on topics related to socialization, leisure, and sexuality.

T11 Determine the cost effectiveness of alternative models of training and use this information to develop fiscally sound

training options.

What can policymakers do to better meet the socialization, leisure, and sexuality needs of a family member with a disability? Policymakers can:

P1 Require that teachers include in the IEP annually as an objective 'making a friend a year'.

P2 Require that teachers include in the IEP annually teaching of a leisure time activity such as as a sport or a handicraft consistent with the individual's preferences and needs.

P3 Implement, monitor, and evaluate interagency agreements to insure coordinated and comprehensive programming in meeting socialization, leisure, and sexuality needs across all stages of the family life-cycle.

P4 Provide 12-month education as an option for all students with disabilities who would evidence significant regression, especially in socialization, if the educational program is terminated over the summer months.

P5 Consider the socialization needs of individuals with disabilities in making decisions related to educational, residential, and vocational placements.

P6 Insure the protection of individuals with a disability from unauthorized sterilization procedures.

P7 Require the development of a transition plan from secondary education to adult services by the age of 14 which identifies socialization, leisure, and sexuality goals and the educational strategies which will be followed to accomplish the goals.

P8 Require federally-funded research projects related to the socialization, leisure, and sexuality needs of individuals with disabilities and their families to incorporate a dissemination plan that insures information will be made available to family members.

P9 Provide funding to develop a comprehensive and coordinated clearinghouse of information that can be easily accessed by family members to provide socialization, leisure, and sexuality information on needs in all areas of family life across all stages of the family life-cycle.

P10 Require, if at all possible, the child attend schools attended by chronological-age peers in the same neighborhood.

P11 Mandate that 10% of space in publicly funded recreation centers be reserved for children with disabilities.

P12 Implement, monitor, and evaluate interagency agreements to insure the provision of coordinated and comprehensive transportation to meet socialization, leisure, and sexuality needs.

P13 Require projects receiving federal funds to provide socialization, leisure, and sexuality services to document cost-effectiveness and use data as a guide in future funding decisions.

Model Program Description: Strategies to Respond To Socialization, Leisure, and Sexuality Needs

Families Together, Inc., is a statewide (Kansas), non-profit organization committed to giving families with children with a disability an opportunity to learn and play together in an atmosphere of relaxation and friendship. Families Together holds Family Enrichment Weekends, Family Days, and Family Campouts so that entire families can have fun together as well as having opportunities to learn and share their experiences. These events are normally held in an enclosed convention center with many activities available for both parents and children. Significantly, these events draw parents, siblings, and the individual with a disability, and are a way to provide both leisure for the family and to introduce family members to one another. Members of the Board of Directors are all parents or professionals who are involved in some way with children with disabilities. Some funding for this program currently comes from the U. S. Department of Education. In 1986, the program will be replicated in six communities throughout Kansas. Since funds for the weekends are raised in large part from community donations, the funding process can be a model for other communities. Also, parents seem to be eager and willing to volunteer as organizers and coordinators for these events.

For more information, contact:

Patty Gerdel or Kathy Johnson

Kansas University Affiliated Facility
Bureau of Child Research
University of Kansas
Lawrence, KS 66045

Phone: (913) 864-4950

Cross-Referencing of Needs and Strategies: Socialization, Leisure, and Sexuality

FAMILIES NEED:	Strategies Which Can Be Implemented By: Families	Professionals	Informal	Trainers	Policy-Makers
To identify and meet the socialization, leisure, and sexuality needs of all members.	F1 F2 F3 F4 F5	PS1 PS4 PS5		T2 T4 T5	P2 P4
To create opportunities for the member with a disability to contribute to the socialization and leisure time assets of the family.	F7 F15	PS3			
To identify and operationalize the socialization strengths of family members.	F7 F8	PS2	I1		
To access services related to socialization, leisure, and sexuality needs that are tailored to individual needs.	F8 F9			T1 T3	P2
To access socialization, leisure, and sexuality services that are coordinated across all stages of the family life-cycle.	F12	PS6 PS6		T5 T8	P3 P12
To access socialization, leisure, and sexuality services within integrated community programs and settings.	F11 F16	PS7	I2 I4 I5	T6 T7	P1 P3 P11
To access information on state-of-the-art practices related to socialization, leisure, and sexuality training.		PS9		T10	P6 P8 P9

To access services related to socialization, leisure, and sexuality needs that help insure a positive future for the individual with a disability.	F6 F12	PS10	I3	T9	P5 P6 P7
To network with other families to share information, to offer support and friendship to one another.	F10 F14	PS8	I7		P8
To realize the greatest dividend from socialization, leisure, and sexuality services by insuring maximum cost-effectiveness.	F17	PS11	I6	T11	P13

VI. EMOTIONAL AREA OF FAMILY LIFE

Window into Family Life: Emotional Needs

We spend a great deal of time with my husband's extended family. One of our nieces, who at 15 is only a few months younger than our oldest daughter, is mentally retarded. Because there are nine grandchildren of all ages, we and her grandmother have asked ourselves questions such as: "What should we expect from Angie? What should we buy her for presents? What activities can we suggest when she can't play Monopoly or Clue as do her cousins? How should we treat her?"

Angie's younger sister has now surpassed her mentally. For her, there are questions of Angie's future. Will she as the only sibling be responsible for Angie's future? Other questions she raises are how to describe Angie to new acquaintances, or how to separate herself from Angie so that she can play with whom she wishes. How much responsibility should she have in caring for Angie?

Although I cannot speak for Angie's father, I know he has questions and concerns about her future. He and Angie's mother are divorced; and he has remarried so there are questions not only of custody issues, but also as to how he should play a role in her life.

These are all issues involving feelings, attitudes and emotions of an extended family as it moves across a life-cycle. What is our role as members of Angie's family?

Harriet Shaffer, Aunt

Emotional Needs

FAMILIES NEED . . .

To identify and meet the emotional needs of all family members.

To create opportunities for the member with a disability to contribute to the emotional assets of the family.

To identify and operationalize the emotional strengths of family members.

To access services related to emotional needs that enhance dignity for family members.

To access services related to emotional needs that are tailored to individual needs.

To access services related to emotional needs that are coordinated across all stages of the family life-cycle.

To access services related to emotional needs from within integrated community programs and settings.

To access information on state-of-the-art practices and services related to emotional needs.

To access services related to emotional needs that help insure a positive future for the individual with a disability.

To network with other families to share information and to offer support to one another related to emotional needs.

To realize the greatest possible dividend from services designed to meet emotional needs by insuring maximum cost-effectiveness.

Recommended Strategies to Meet Emotional Needs

What can the family do to better meet the emotional needs of the family member with a disability? The family can:

F1 Identify the priority emotional needs of all family members and develop options for responding to them.

F2 Provide information to professionals on the priority emotional needs of the family and preferred options for responding to them.

F3 Identify the emotional strengths of the individual with a disability and develop future goals to capitalize upon these strengths.

F4 Work with professionals to develop an educational program that fosters healthy emotional development.

F5 Encourage respect for the individuality of all family members.

F6 Identify ways in which the entire family can enhance the self-esteem of all family members.

F7 Develop family communication styles that enable all family members to confront their feelings about disability and receive support to make constructive emotional responses according to their individual needs and preferences.

F8 Communicate with all family members concerning the nature and implications of the disability and constructive strategies for responding to the queries of others.

F9 Insure that all family members have individualized options for responding to their emotional needs across all stages of the family life-cycle.

F10 Insure that family members are prepared for the emotional re-adjustments necessary at each new stage of the family life-cycle.

F11 Encourage community professionals who provide emotional support and counseling (e.g., counselors, psychiatrists) to develop expertise in disability issues to increase their effectiveness in responding to the needs of families who have a member with a disability.

F12 Network with other family members to gain information about options for responding to emotional needs.

F13 Access peer support as a strategy for responding to the emotional needs of all family members.

F14 Become informed about the relative public and private cost of different options for meeting emotional needs of families and advocate for programs that have been determined to be cost-effective.

What can the professional service network do to better meet the emotional needs of the family member with a disability? The professional service network can:

PS1 Identify procedures for assisting families to identify and prioritize emotional needs of all family members and to develop options for responding to them.

PS2 Assist families in dealing with emotional concerns of all family members.

PS3 Identify and communicate the emotional strengths of the individual with the disability to the family.

PS4 Insure that programming to respond to emotional needs is consistent with family values and preferences.

PS5 Assist the individual with a disability in identifying and accentuating positive contributions to the family.

PS6 Insure that families are prepared emotionally to make transitions to new service programs and new life-cycle stages.

PS7 Provide opportunities for individuals with a disability and their families to interact with positive role models related to healthy emotional development.

PS8 Encourage effective networking of families for the purpose of sharing information and providing support related to emotional needs.

PS9 Provide readily available information to families on topics such as communication skills, characteristics of 'hardy' families, assertiveness training, coping strategies and peer support.

PS10 Provide training for professionals in differences in cultural and ethnic identity and values as related to emotional needs.

PS11 Establish the cost-effectiveness of programs that respond to emotional concerns and use this information to increase cost-effectiveness and advocate for programs that are fiscally sound.

What can the informal community network do to better meet the emotional needs of the family member with a disability? The informal community network can:

I1 Highlight the emotional needs and strengths of families of individuals with disabilities through the media.

I2 Develop volunteer programs to provide emotional support to families of individuals with disabilities.

I3 Provide opportunities for emotional support to be provided in community public spaces.

I4 Encourage networking of families for the purpose of sharing information and providing support related to emotional needs.

I5 Encourage community agencies which may focus on specific disabilities to provide peer support for family stress.

I6 Highlight cultural and ethnic identities and values of families of individuals with disabilities through the media.

I7 Promote the utilization of community programs (e.g., mental health centers, religious organizations) to meet the emotional needs of families.

I8 Determine the cost-effectiveness of meeting the emotional needs of individuals with disabilities within integrated community settings and disseminate this information through the public media.

What can trainers do to better meet the emotional needs of the family member with a disability? Trainers can:

T1 Incorporate into preservice training programs of all professionals with responsibilities for working with families information to enable them to establish constructive and individualized family-professional partnerships responsive to emotional needs.

T2 Develop comprehensive and sequential inservice training programs for all professionals with responsibilities for working with families to enable them to establish constructive and individualized family-professional partnerships responsive to emotional needs.

T3 Provide inservice training in various cultural and ethnic identities and values related to emotional needs.

T4 Provide training opportunities for all interested families to enable them to meet the emotional needs of all family members.

T5 Provide training opportunities to all interested persons in the informal community network to prepare them to contribute effectively to the emotional needs of individuals with disabilities.

T6 Incorporate into the educational curriclum of all elementary and secondary students information about the emotional needs of peers with disabilities and ways they can foster emotional development.

T7 Provide training opportunities for individuals with disabilities and their families in strategies for fostering emotional development and self-esteem.

T8 Provide accessible and comprehensive clearinghouses of information that family members can access to gain information on topics related to emotional needs of family members.

T9 Provide training in counseling skills to those families interested in this training.

What can policymakers do to better meet the emotional needs of the family member with a disability? Policymakers can:

P1 Insure that all individuals with emotional disabilities are provided with education, habilitation, employment, and residential living in the least restrictive environment.

P2 Insure access to appropriate service systems for individuals with a "dual diagnosis" (e.g., mental retardation and mental illness).

P3 Fund research characteristics of "hardy" families that could be shared with other families that have difficulties and disseminate this information.

P4 Fund research on the development of self-concept and self-esteem in the child with disabilities and disseminate information from this research to families.

P5 Provide funding to develop a comprehensive and coordinated clearinghouse of information that can be easily accessed by family members to provide information in areas of emotional support.

P6 Implement, monitor, and evaluate interagency agreements to insure the provision of coordinated and comprehensive transportation to meet the needs of family members in accessing emotional support.

P7 Require agencies to determine the cost-effectiveness of their programs and use this information in insuring that programs are fiscally sound.

Model Program Description: Strategies to Respond to Emotional Needs

The SEFAM (Supporting Extended Family Members) model developed by staff at the Experimental Education Unit, University of Washington, helps family members who have been traditionally underserved adjust to life with a child with a disability in the family. The Fathers Program addresses the special needs of fathers through a biweekly, 2-hour program of information and support. The local program serves from 20-30 fathers and their children, and staff currently provide outreach technical assistance and training to others who wish to serve fathers in their communities. Staff have written a handbook to help others establish a fathers' program. Two other programs have also been developed, one for siblings and one for grandparents. Both offer quarterly workshops for these family members. The sibling workshops help young children ages 9 and older to better understand their brother's or sister's disability, and to meet and make friends with other siblings who share their unique concerns. The quarterly grandparent workshops, offered under the auspices of the local Association for Retarded Citizens as a parent training project, similarly offer an information and peer support component. A handbook has been written to help others organize sibling workshops, and a handbook on the grandparent workshops is being prepared. Staff have also written a handbook for young siblings themselves, ages 9 years and older. The book describes worries and concerns that siblings commonly experience, and it explains disabilities and medical/educational terms that often confuse brothers and sisters of children with special needs.

For more information contact:

Dr. Rebecca R. Fewell
Mr. Donald J. Meyer

University of Washington
EEU WJ-10
Seattle, WA 98195

Phone: (206) 543-4011

Cross Referencing of Strategies for Emotional Needs

FAMILIES NEED:	Strategies Which Can be Implemented By: Families	Professionals	Informal	Trainers	Policymakers
To identify and meet the emotional needs of all family members.	F1 F7 F8	PS1 PS2		T1 T2 T4 T9	P2
To create opportunities for the member with a disability to contribute to the emotional assets of the family.		PS5			P4
To identify and operationalize the emotional strengths of family members.	F3	PS3	I1	T7	
To access emotional needs planning services and that enhance dignity for family members.	F5 F6	PS4 PS7 PS9		T6	P1
To access emotional planning services that are tailored to individual needs.	F11 F13	PS4 PS10	I5 I6	T3	P3
To access emotional needs planning services that are coordinated across all stages of the family life-cycle.	F9 F10	PS6			
To access emotional services from within integrated community programs and settings.			I2 I3 I7	T5	P6
To access information on state-of-the-art practices related to emotional services.		PS8 PS9		T8	P5
To access services related to emotional needs that help insure a positive future for the individual with a disability.	F2 F4				
To network with other families to share information and to offer support to one another.	F12	PS7	I4		

To realize the greatest possible dividend from services designed to meet emotional needs by insuring maximum cost-effectiveness.	F14	PS11	I8	T13	P7

VII. REACTIONS OF TWO FAMILY MEMBERS TO THIS REPORT

We asked two people who belong to families with members with disabilities to read and react to our report. First, we asked them to describe their own life with disability and then we asked them to note strategies which could fill their current needs and/or strategies which have proven helpful to them in living out their lives. The two people who discussed the report with us are Glen, who has a disability involving paralysis of the lower extremities, and Gloria, who is the mother of a son with emotional disabilities. We hope their reactions to the strategies suggested in the five areas of family life bring a picture of real life to the document. We think they serve as an apt conclusion.

* * *

Gloria is a single black woman who adopted Adam when he was 5 1/2 years old. He is now 11. Gloria had specifically requested adopting a child who did not have special needs. She did not receive information about Adam's emotional disabilities at the time of his adoption, and is currently filing suit against SRS because they did not inform her of the boy's emotional problems and background.

When Gloria adopted Adam she was told that "with love and stability, he would be fine." Problems arose when Adam went to kindergarten. He threw violent temper tantrums, and the staff referred him to a personal social adjustment (PSA) program in Topeka, because the district in their small town does not have a personal social adjustment classroom. During the past school year, Adam was in a class at the Topeka Educational Center for the most severe cases of personal social adjustment. At the end of the school year, Gloria was told that they advised not placing him in a personal social adjustment class in the fall of 1986, but that they recommended placement in Topeka State Hospital, a state institution for persons with mental illness.

Thus, Gloria's concerns are for the immediate future of Adam. Gloria said that she is the only person who can control Adam, and that he has never thrown a tantrum in her presence. She has, however, seen him tantrum to the extent that it takes several people to restrain him. Thus, she is aware of his problems, but she also has concerns that educational personnel have set him up for failure.

Gloria herself is a professional in the special education field, coming into it after her adoption of Adam. She was in the insurance business when she adopted Adam, but she was unable to continue in that field because of Adam's demands on her. Also, she was interested in becoming as informed as possible about emotional disabilities, and thus she went back to school to get a master's degree in special education. She now teaches students with severe multiple needs in the Topeka school district. She

has been teaching for the past two years.

Adam is a biracial child and had at one time lived with a white foster care family. Gloria's family is accepting of his biracial background.

Gloria identified positive contributions of Adam to her life as those of his being a caring person, an extremely polite child to whom she has not taught politeness. She said that he has a sense of humor. He beams with his successes. He has taught her patience, and when she works with families of children with disabilities, she can stop and say, "Is this what I would want done to my child?" Her life with Adam has given her a goal of dignity and respect toward others.

Daily Living and Health Care

In the area of daily living and health care, Gloria emphasizes that she would like to receive respite services, specifically up to 20 days of respite a year. She presently pays a sitter during the mornings while she works and has had problems getting competent sitters--she said "some have lasted 2 months; some 2 hours."

She says that she had received some support on daily problems from networking with other parents as well as personal support from her own initiatives in gaining expertise. She stresses the need for access to state-of-the-art information from professionals on health services, respite care, attendant care, accessibility, time management, behavior management, and problem-solving.

Gloria indicates relatively few needs and concerns in this area as compared to other areas. She looks at the family itself and at policymakers as change agents in this process.

Socialization, Leisure, and Sexuality

Gloria identifies several needs in the area of socialization, leisure, and sexuality which can be met by an array of providers, primarily by family members. Gloria wishes family members would provide friendship, love, and affection for Adam. She describes her own extended family and how she wishes that her two brothers and one nephew would spend more time with Adam. They play with him when they come to her house, but do not extend invitations on their own. She identifies all the other strategies as useful ones to be implemented by a family.

Professionals, she feels, need continuing education in this area as well as changes in their training to help them understand the needs of persons with emotional disabilities for leisure activities, socialization, and sexuality.

In the policy area, Gloria supports the concept of neighbor-

hood schools and of reserving a percentage of space in community centers for activities for persons with disabilities. Both of these policy changes would affect her situation directly as at present her own school district cannot provide a class for Adam, and so she drives him to the school where she teaches and then he walks several blocks to the school he attends. He also has only one summer activity.

Financial, Legal, and Advocacy

Gloria expresses many needs in this area. Here again, she first looks to strategies which the family with assistance can implement: financial planning, advocacy, future planning. Thus, she supports those strategies establishing professional school training via curriculum changes. She supports a number of strategies in the ara of policy changes ranging from expanding state protective and advocacy services to providing an additional tax exemption for a family member with disabilities.

Gloria believes that professionals, even special education professionals, do not really understand the needs of people with emotional disabilities. She considers this disability to be one of the least well understood. Gloria views a child with emotional disabilities as having long-term financial, legal, and advocacy needs.

Educational and Vocational

In the area of educational and vocational needs, Gloria indicates that families can implement many strategies including evaluating family needs, receiving teaching services in the home, networking, future planning, family support, knowledge of future options, continuing education, and knowing about educational opportunities. She sees the professional support system as the one most likely to implement these strategies especially those of helping the family teach skills and network with other families.

A need overlapping in several areas is that of finding a mentor or a positive role model for Adam. Gloria feels that the professional service delivery system spends a lot of time worrying about controlling Adam and very little time in actually educating him. Because his teachers have recommended that he not return to his personal social adjustment classroom, but that he be hospitalized, Gloria is understandably very present-oriented and does "not want him to go to Topeka State Hospital and be all drugged up."

Emotional

Gloria identifies a number of strategies to respond to emotionally-related needs. These strategies can be undertaken by families and professionals. She concurred with almost every strategy in the family section, ranging from identifying strengths to developing individual options to networking. In the area of professionals, she highlights the importance of providing

positive role models for Adam, saying that so often the kids in his classes are not those whom she would like Adam to model himself after.

This area of family life is one in which she identifies a variety of strategies which the informal network could implement: providing media involvement, networking, providing ethnic information, and especially encouraging community groups in providing meeting places. In the area of policy, she stresses the importance of providing funding for information clearinghouses for parents.

In an example relevant to all areas of family life, Gloria describes Adam's participation in a summer bowling league, the only summer activity she has found for him. The other children in the league are "normal", and their parents drop them off at the bowling alley while Gloria stays and supervises. She has seen several children behave in ways which she says would guarantee placement in a personal social adjustment class, while Adam behaves perfectly. She finds this ironic that Adam's behavior at times limits his access to other activities, while a "normal" child is apparently free to behave in a variety of ways.

* * *

At 35, Glen is a husband, father, graduate student, sports enthusiast, and a friend of many people. He has a particularly warm and friendly style and says that he views himself as an "encourager of others." When Glen was 15, he was with seven others in a car that crashed into a tree. The accident resulted in his being paralyzed from the waist down. He gains his mobility through a wheelchair.

In reflecting on his accident, Glen noted the tremendous support that he received from his parents. They supported his independence and did not over-protect him as he continued through his adolescent years and entered adulthood. He had some emotional reactions in adjusting to his disability in the time that immediately followed the accident. Glen remembers feelings of self-consciousness when he tended to withdraw from some high school friends and activities. A major catalyst for Glen in terms of reassessing his life was a "spiritual-awakening" that occurred late in his junior year. Glen describes how his bitter and angry attitude mellowed and became more optimistic. He started reaching out to others and got involved in many activities during his senior year such as managing a wrestling team and participating in a singing group.

Glen describes his college years as enjoyable and productive as he excelled in his course work and was a campus leader in student government activities. He earned a bachelor's degree in sociology and psychology and describes himself as "headed toward a vocational rehabilitation counseling job." For 13 years, Glen worked at the Mayo Clinic in therapeutic recreation. During this time, he met Nancy, a rehabilitation nurse whom he had met

earlier in college, and the two of them decided to marry. A couple of years later they started proceedings for adoption and had the good fortune of adopting two beautiful children from Korea, Elisha and Eric. Glen places strong priority on his family and on spending quality time in family recreation.

Daily Living and Health Care

Glen believes that one of the most difficult areas he has experienced in accessing health care is the pre-existing conditions clause in insurance policies that serve to exclude individuals with disabilities from health coverage and the limitations of insurance policies on health care providers. He advocates for insurance options tailored to individual needs that maximize quality of care rather than compromising it.

In terms of daily living, he believes particularly helpful strategies include providing individuals with a disability with positive role models, insuring the availability of attendants to achieve personal independence and incorporating independent living philosophy into preservice and inservice programs. He strongly supports the enforcement of Section 504 regulations to insure equal access to federally funded programs in the areas of daily living and health needs.

Glen reports that he sometimes feels frustrated that he is not able to do some of the tasks that need completion around the house such as getting something out of the attic or getting up on a ladder. A particularly helpful strategy that he has used is exchanging chores with neighbors. He has a neighbor who is deaf who needs help making phone calls. Glen helps him with the phone calls, and the neighbor has helped Glen put in a ceiling fan. Glen believes that much assistance can be gained through the "least restrictive environment" of the informal support network.

Socialization, Leisure, and Sexuality

Glen believes very strongly that more attention needs to be given to recognizing the sexuality needs of people with disabilities. He has worked as a group leader in situations in which individuals explore together sexual attitudes, curricula for sex education, and various options for sexual expression. One of the reasons he supports the need so strongly is that in his rehabilitation experience physicians never talked with him about sexual issues nor did other persons in his support system. He and his wife, Nancy, learned together about sexual options through discussions and exploration.

In addition to supporting such a range of strategies to meet sexuality needs, Glen also strongly believes that socialization and leisure are very important areas to be addressed. He believes that his needs are largely met in these areas through a variety of hobbies such as playing a guitar, playing raquetball and basketball, and racing in his chair. He says that it took him a while to get involved in racing as an "athlete", not as "a

person in a wheelchair". He suggests that "mentor connections" are helpful in assisting people with disabilities to gain access to socialization and leisure opportunities.

Financial, Legal, and Advocacy

Glen indicates that he has not had extensive financial needs associated with his disability since his rehabilitation after the automobile accident. He does, however, have excess costs associated with his wheelchair and home modifications. A major financial barrier that he indicated faces people with disabilities is being identified as a "rated sector" for life insurance companies. This means that some persons are unable to obtain life insurance and others have to pay up to double the cost of regular life insurance. This is a major financial barrier for many people with disabilities and should be removed through legal advocacy.

Another policy need that Glen emphasizes is the disincentives to work for many people with disabilities in light of the eligibility requirements for Medicaid and Social Security Disability Income. He sugests that policymakers explore alternatives to ensure that financial benefits do not become disincentives to productivity.

Finally, Glen shares the fact that he has tended to pursue assistance in environmental accessibility from the informal community network rather than through services for which he would have to pay. For example, in widening the door to the bathroom in his home, he sought the help of a friend rather than paying a carpenter to come in and do the work. He then looked for an opportunity to reciprocate with the friend in terms of taking him out for a meal.

Educational and Vocational

Glen has been able to access major benefits to assist him with his educational goals from vocational rehabilitation in the form of payments for tuition, books, room and board. He earned a bachelor's degree in Psychology and Sociology and a master's degree in Educational Psychology and Counseling. He perceives that having a disability was a definite asset to him in his masters program because of his first-hand understanding of disability. He indicates that helpful educational strategies are to promote consumer control in planning educational and vocational goals, having access to mentors, and insuring that buildings providing educational and vocational opportunities are accessible.

He suggests that people with disabilities can be excellent guest speakers in preparing elementary and secondary school students with information about the needs and strengths of people with disabilities, and he sees a major role for policy-makers in insuring that educational facilities are provided in the least restrictive setting.

Emotional

Glen recognizes in his own rehabilitation process that he has gone through different phases and stages in emotional reactions. He indicates that the first six months were the hardest in his feelings of frustration and isolation, but since that time he has learned to "take things as they come," to "form meaningful relationships with others," and "make the best of situations." He suggests that all people increase their understanding of the emotional needs of persons with disabilities by giving more attention to emotional needs in preservice training programs and including more information about the emotional needs of peers with disabilities in the educational curricula of all elementary and secondary students. He believes that a particularly helpful strategy for people with disabilities in their dealing with everyday problems is peer counseling. Another major strategy that Glen suggests is to fund research on the development of self-concept and self-esteem in children with disabilities and other family members to provide a knowledge base to assist families in the most helpful way possible.

* * *

The ultimate goal then of family systems and disability research and education must be to work toward and for the enhancement of family life where there is a member with a disability. All segments of society can and should be involved. There is a part to play for all aspects of society -- trainers, policy makers, the service delivery system, the informal community network, and the families themselves.

EXECUTIVE SUMMARY

As members of families of people with disabilities and/or professionals who work with people with disabilities, we incorporated our expertise and knowledge of state-of-the-art practice into these recommendations.

We use the term "family" to mean the unit of people who are related by blood, marriage, or deliberate association and who share responsibilities for meeting individual or collective needs. The areas of those needs are the areas of family life. These areas of family life can be categorized into the following five areas: Daily Living and Health Needs; Educational and Vocational Needs; Financial, Legal, and Advocacy Needs; Socialization, Leisure, and Sexuality Needs; and Emotional Needs.

We define disability broadly to cover a wide range of conditions. Each type of disability has some unique characteristics that create specific needs for families; however, families with members having different kinds of disabilities usually find that many of their needs are similar. Throughout this document we address the needs of families in a generic manner.

Seven premises shape the specification of needs and development of strategies for enhancing family life included in this document. These premises are important as a basis for understanding and acting on the needs and strategies. These premises include: (1) Disability creates special needs in all areas of family life; (2) Individuals with a disability make positive contributions to their families; (3) Families have individualized needs requiring individualized responses from a continuum of appropriate services; (4) Family needs should be met within

integrated community services and environments; (5) Families should have access to information; (6) Families need to expect confidently that their member with a disability will have a positive future; and (7) Strategies for enhancing family life must be cost-effective.

In looking at the previously-listed five areas of family life separately, we suggest strategies which can be implemented by various persons or groups, including the family, the professional service delivery system, and informal community network, trainers, and policy makers. All of the strategies are based upon the above-discussed sets of values and are derived from them.

Currently in the state of Kansas, the Exceptional Family Information Network at the University of Kansas is directly responding to requests made by parents of people with disabilities. Some examples of the type of requests made to the state's "800" phone number clearly show that our categorization of the types of family needs and of those who could respond to them are right on target.

For example, a family in a small town in north central Kansas received a pamphlet from us and wrote to us telling us about their 11-year-old daughter who is severely mentally disabled, who has Rhett's Syndrome, and now is at home, physically unable to attend school any longer. This family asked for information about Rhett's Syndrome and for information about respite care. They wanted information useful to them in the area of DAILY LIVING AND HEALTH. The family itself is providing the

daily health care; an occupational therapist is their current link to the professional delivery system; the informal community system could provide respite services if trained; trainers could provide training in in-home care and in respite; and policy makers could provide case manager services.

Another family, headed by a single mother, called and asked for help in vocational placement for her adult son. The mother had not previously made plans for her son's placement, but she now needed to because she herself needed to find a job. This is an example of EDUCATIONAL AND VOCATIONAL NEEDS. Here again, the family can provide direction on deciding on a vocational placement; the professional service delivery system can provide case management and/or vocational counseling; the informal community can provide respite for this mother; the trainers can provide training in helping adults access the system; and policy makers can mandate these services.

In the area of FINANCIAL, LEGAL, AND ADVOCACY several situations from the request files come to mind. Common among them is the frustration expressed by the parent at what the parent considers to be the inappropriate placement of the child in some type of special education program. The family can express its preferences; the professional service delivery system can respond through the IEP process and through grievance procedures; the informal community network can be available in providing support groups; trainers can train parents in their rights and responsibilities; and policy makers can review procedural safeguards.

A specific request exemplifying SOCIALIZATION, LEISURE, AND SEXUALITY NEEDS came from a mother of an infant with a visual

impairment who asked for information on acceptance so that she might share that information with her church's nursery staff. The mother feared that the nursery attendants would soon ask her not to bring the baby to the nursery. Here the family can provide reassurance and information about the child; the professional delivery system can work through religious organizations to give out accurate information; the informal community system, in this case the church, can examine its own attitudes; trainers can provide training on acceptance; and policy makers can encourage acceptance.

Finally, in the area of EMOTIONAL LIFE, a number of requests have come to the network from those asking for hook-ups with support groups. One poignant request came from a father who "wanted to talk with some parents just like me." This particular father needed reassurance and support from other parents, especially because he was pursuing an advocacy relationship with the school system. Families can express their needs for support; the professional service delivery system can provide this help by encouraging support groups to meet and allowing them to be run by parents; the informal community system can provide meeting spaces and funds; trainers can provide ideas on effective functioning of support groups; and policy makers can fund innovative support group models.

In presenting these examples of requests received by the Exceptional Family Information Network in Kansas, the validity of our areas of daily life and of the process of developing strategies is demonstrated. Contained within this paper are many

examples of strategies which can be implemented by families, the professional service system, the informal community network, trainers, and policy makers.

In addition, within each area of family life, at least one conference participant wrote a vignette of his or her own family needs; and then one model program is described that has the potential of being responsive to the family needs discussed.

Whether a strategy is as specific as "provide tax incentives to industries who employ persons with disabilities" or as general as "display love and affection towards the individual with a disability as with any family member", our goal is the same: To enhance family life where there is a member with a disability. In this paper, we give strategies which may be implemented by any of the five groups identified. When groups do implement these strategies, we will move closer to the enhancement of family life for particular families and for our society as a whole.

Ann Turnbull, Ed.D.
National Center for Networking Community Based Services
Georgetown University Child Development Center
3800 Reservoir Road, N.W.
Washington, D.C. 20007